Post-exertional malaise (PEM)

Post-exertional malaise (PEM) is a symptom of ME/CFS, and half of people living with long COVID also have it. It is important to understand PEM, especially if symptoms feel worse, either when doing more activity or soon after an activity.

PEM can start right after an activity or up to a few days later. It can last for several days or even longer. Everyone is different[3,4].

For people who are very sick with ME/CFS or long COVID, PEM may happen after having a shower, walking to the kitchen, or even rolling over in bed.

If people have PEM, the best thing to do is rest. It may take days, weeks or even longer to feel better[5,6].

Common symptoms of PEM?

PEM makes symptoms worse, such as:
- Pain
- Sleep
- Brain fog
- Feeling like you may get the flu
- Muscle weakness
- Sensitivity to noise, light or touch.

It is helpful to think about PEM like the energy in a battery

The body of someone with ME/CFS is like a broken battery that doesn't charge properly and drains quickly.

When the ‘body battery’ gets low, your body cannot make or use energy normally. Symptoms worsen and movement becomes more challenging.

If you keep being active without resting, your body’s energy levels deplete. Like an empty battery on your phone that has turned the colour red.

It is important you rest before your body's battery is red. If activity makes you worse, do NOT push through or follow programs that worsen symptoms; take a rest or do less.

Exercise and PEM?

Researchers have studied PEM by having people exercise as much as possible for two days. People who had PEM did worse on the second day. Their bodies didn't recover normally, and researchers found they had trouble with:

- Making or using energy
- The immune (body protection) system
- Moving blood and oxygen around the body [3,7].

What should people do if they experience PEM?

Remember

- The body battery of someone with ME/CFS or long COVID is different from a healthy person
- People with ME/CFS or long COVID cannot do the same number of activities they could before they got sick
- What you can do in one day will be less than before you got sick
- The amount you can do each day will be different - and every person with ME/CFS and long COVID is differen
- You will need to make hard choices about what activities you do, so you don't make your symptoms worse.

Reference

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